PEER REVIEW HISTORY

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ARTICLE DETAILS

TITLE (PROVISIONAL)	Cause of Death and Potentially Avoidable Deaths in Australian Adults with Intellectual Disability Using Retrospective Linked Data
AUTHORS	Trollor, Julian; Srasuebkul, Preeyaporn; Xu, Han; Howlett, Sophie

VERSION 1 - REVIEW

REVIEWER	Anne Kavanagh University of Melbourne, Australia
REVIEW RETURNED	22-Sep-2016

GENERAL COMMENTS	This is an excellent, well written paper with clear research questions. It makes a substantial contribution to the literature. Little is known in Australia and internationally about premature mortality among people with intellectual disabilities. This paper fills that gap and highlights the significant inequalities in health people with intellectual disabilities experience. The authors clearly outline the potential limitations in the study. My only concern was their method for ascertaining cause of death in the ID cohort. It is difficult to follow the description. A diagram on sources of data (general population and ID) and coding of deaths might help. I was concerned about the validity of the coding of deaths from the RBDM data by the medical practitioner. It would have been better to have at least two coders as misclassification of cause of death in the ID cohort could introduce substantial bias. Could the authors provide some estimates of the validity of the classification of cause of death data from the RBDM and/or estimate the potential impact of misclassification on estimates of causes of death and avoidable mortality.

REVIEWER	Dr Jane McCarthy King's College London, UK
REVIEW RETURNED	30-Sep-2016

GENERAL COMMENTS	This is a well written paper and provides further evidence at an international level on the health inequalities experienced by people with intellectual disabilities. The challenge is changing Policy & Practice.

REVIEWER	Prof Mary McCarron Trinity College Dublin Ireland
REVIEW RETURNED	02-Oct-2016

GENERAL COMMENTS	This is a very well written article which is timely and will make an important contribution. A few minor issues include i) at times it is difficult to tell if a number in brackets refers to a reference or is a result in the paper so perhaps better labeling could be used ii) in Table 1, keep the CI's on one line iii) The layout of Table 2 could be improved for greater clarity iv) The paragraph on page 13, lines 21-31 could be expanded to add greater clarity and more text to accompany figure 1 The paper clearly outline is own limitations and completes a checklist of items that should be included in reports of cohort studies.

REVIEWER	Philip McCallion University at Albany USA
REVIEW RETURNED	09-Oct-2016

GENERAL COMMENTS	This is a very good paper which will add to the literature on mortality in this population. 1. a number of statements on mortality and multimorbidity are unreferenced 2. there is no consideration of the quality of cause of death data 3. no consideration of the completeness and representativeness of the dataset set from which participants with ID are drawn 4. Comparison group is not described in abstract 5. With the decisions to drop a number of deaths difficult to agree that the sample remains representative 6. the impact of lower rates of accidental death on sex-based differentials in mortality is an interesting finding - would be helpful if this data more clearly emerged in the results to set up for later discussion. 7. No rationale is given for choosing age 75 as the base for calculations 8. references need some editing 9. abbreviations should be spelled out the first time they are used in the text 10. Readers should be guided on how to interpret some of the mortality findings and how dramatic differences are with the comparison group.

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VERSION 1 – AUTHOR RESPONSE

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Reviewer: 1

The authors clearly outline the potential limitations in the study. My only concern was their method for ascertaining cause of death in the ID cohort. It is difficult to follow the description. A diagram on sources of data (general population and ID) and coding of deaths might help. I was concerned about the validity of the coding of deaths from the RBDM data by the medical practitioner. It would have been better to have at least two coders as misclassification of cause of death in the ID cohort could introduce substantial bias. Could the authors provide some estimates of the validity of the classification of cause of death data from the RBDM and/or estimate the potential impact of misclassification on estimates of causes of death and avoidable mortality.

Our deaths data is drawn from two reputable national sources (the Australian Bureau of Statistics (ABS) and Registry of Births Deaths & Marriages (RBDM)) and is collated according to standard international best practice. Apart from coronial inquiries, the cause and date of all deaths must be certified by a registered medical practitioner and the certificate registered by RBDM in each State or Territory. The vast majority of non-coronial deaths are registered with the relevant RBDM within four weeks of the date of death; however coronial inquiries can take longer. Details of all registered deaths are then forwarded to the ABS. The ABS then check and code the information, according to a standardised and internationally accepted coding algorithm (ICD-10).

Our own coding of cause of deaths which were not already coded by the ABS mirrored that performed by the ABS and utilised the standardised coding approach outlined in the International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10) Mortality Manual. We ensured the accuracy of our coding by first using the 155 cases with both RBDM free text cause of death and ABS for training purposes. In our view this was a rigorous process and the same as that used to derive the national data set (ABS). Independent validation was not possible as those cases for which both sets of deaths data was available were used in training to ensure accuracy of coding.

In order to improve the manuscript, we have:
- added more detail in the methods section on page 7 to highlight the specific process we followed.
- Indicate the specific source and number of cases from which cause of death data was derived
- acknowledged the potential limitations of the coding methodology in the limitations section of the manuscript on page 19 which now reads "Independent validation was not performed on our coding of deaths data for those deaths which were not previously coded by RBDM. However, a rigorous coding process was undertaken which mirrored that used for the national data set (ABS)."

Reviewer: 2
This is a well written paper and provides further evidence at an international level on the health inequalities experienced by people with intellectual disabilities. The challenge is changing Policy & Practice.
We agree wholeheartedly with this comment and we are in frequent discussions with the Australian and NSW Governments over the policy and practice implications of our findings. Our original manuscript has a discussion section which highlights the implications for policy and practice (pages 18-19), and this has not been expanded owing to word limitations.

Reviewer: 3
This is a very well written article which is timely and will make an important contribution.
A few minor issues include
i) at times it is difficult to tell if a number in brackets refers to a reference or is a result in the paper so perhaps better labeling could be used
Thank you for this helpful suggestion. We have changed the brackets of references from () to [] to reduce confusion and, have also placed references after '.'.

ii) in Table 1, keep the CI's on one line
CI's are now on one line in our word document, however, there could be some changes in the format once it is converted to PDF. Should the article be accepted for publication, we can ensure this is reflected in the publication proofs.

iii) The layout of Table 2 could be improved for greater clarity
We have enhanced the layout of Table 2 by adding spaces before each cause of death.

iv) The paragraph on page 13, lines 21-31 could be expanded to add greater clarity and more text to accompany figure 1

As the reviewer requests, we have amended the paragraph for greater clarity. It now reads "Age-specific potentially avoidable death rates for the ID and comparison cohorts are shown in Figure 1, and in the supplementary Table 2. People with ID had higher age-specific avoidable death rates than the comparison group for both ABS Convention and 'Revised' coding methods, with the latter being of slightly greater magnitude"

Reviewer: 4

1. a number of statements on mortality and multimorbidity are unreferenced
We have added references to the section where mortality and multimorbidity were unreferenced.

2. no consideration of the quality of cause of death data
Please see our above detailed response to the very similar comment by reviewer 1.

3. no consideration of the completeness and representativeness of the dataset set from which participants with ID are drawn
Our disability services dataset (DS-MDS) keeps records of all people registered for services mainly for administrative purposes. As indicated in the manuscript we received records of everyone who registered to use the service and linked that to mortality data using a Statistical Linkage Key (SLK581). As acknowledged in the limitations section of our manuscript, this resulted in identification of a population with ID who represented 0.6% of the NSW population. As the DS-MDS is a sample of disability service users, it is likely that people with more severe levels of disability are therefore over-represented. The specific group we are purporting to represent is reinforced once again in paragraph 2, on page 19 "our sample is representative of disability service users with ID". Further, we wish to indicate that the issue raised is essentially unavoidable and affects all such research internationally which relies on data derived from large administrative datasets.
As the SLK581 is known to have lower rates of linked records than using the Master Linkage Key, we also evaluated the robustness of the linkage process. This proved robust, as only 638 (0.8%) individuals were excluded due to incomplete linkage key. Hence, we are confident that the data is as complete as it can be.

4. Comparison group is not described in abstract
The Comparison cohort has now been added in the 'Design, setting and participants' section. It now reads "Design, setting and participants: Retrospective population-based standardised mortality of the ID and the Comparison cohorts. The ID cohort comprised of 42,204 individuals who registered for disability services with ID as a primary or secondary diagnosis from 2005 to 2011 in New South Wales (NSW). The Comparison cohort information was obtained from published deaths in NSW from the Australian Bureau of Statistics (ABS) from 2005-2011."

5. With the decisions to drop a number of deaths difficult to agree that the sample remains representative
We used all deaths to calculate standardised mortality rates and comparative mortality figures. Hence, we believe that our CMFs results are representative of people with ID who receive disability services. For the cause of death description, it was of course necessary to exclude deaths with unknown causes of death (13% of all deaths). This is unavoidable with such datasets, and invariably, no information is available regarding why cause of death is missing. However, as 87% of the total deaths were used for the cause of death analysis, we are confident that the results are robust.

6. the impact of lower rates of accidental death on sex-based differentials in mortality is an interesting finding - would be helpful if this data more clearly emerged in the results to set up for later discussion. We have addressed this issue by the addition of a new paragraph detailing top three leading causes of death by age group and sex for the ID and the Comparison cohorts and added an additional table (Table 3), page 12, paragraph 2.

7. No rationale is given for choosing age 75 as the base for calculations
We chose age 75 as the base calculations to be consistent with the definition of the potentially avoidable deaths. We have made this clearer by changing the YPLL section on page 8 to "The YPLL is an indicator for premature mortality and is the total number of years not lived by an individual who died before a pre-specified age. To be consistent with the definition of potentially avoidable deaths, we considered people who died before 75 years of age as premature deaths"

8. references need some editing
The references have now been checked for inconsistencies.

9. abbreviations should be spelled out the first time they are used in the text
We have now spelt out abbreviations the first time they are used in the text.

10. Readers should be guided on how to interpret some of the mortality findings and how dramatic differences are with the comparison group.
We have rewritten the mortality findings, and emphasise the interpretation of the Comparative Mortality Figure, it now reads "People with ID in the 20-44 age category had four times the death rate of the comparison group (Comparative mortality figure (CMF): 4.0; 95% CI 3.1-5.2). For people with ID in the age category of 65 years and over, there was no evidence to support excess deaths above the comparator (CMF: 1.0; 95% CI 0.8-1.2) (Table 1)." etc

VERSION 2 – REVIEW

REVIEWER	Philip McCallion University at Albany Albany NY USA
REVIEW RETURNED	04-Dec-2016

GENERAL COMMENTS	All concerns have been addressed